

## Emotional aspects of blood and marrow transplantation: What you may feel; how we can help

### Emotional experience

We all have unique ways to cope with stress in our lives. The stress of transplantation—before, during, and after transplant—will also be experienced uniquely by anyone going through this process.

Despite these differences, though, most people undergoing blood or stem cell transplantation will share common feelings and concerns.

While not everyone will feel distress, there is no doubt that going through a transplant can be physically, emotionally, and psychologically taxing for both the patient and his/her family.

It is important to know that the team is available to assist you and your family members through each step of the transplant.

### The decision to pursue transplant

Being diagnosed with a life-threatening illness can be a stressful and traumatizing event in itself. Pursuing transplantation carries not only a sense of excitement and hope but also a sense of worry or fear for what will come.

Others fear that treatment will not work.

Changes in emotional reactions are common. For example, one day you might feel tired and frustrated. Other days, you may feel irritable and sad. It is also not uncommon to feel all of these emotions at once.

### What to do?

It is important to let a member of your health

care team know how you feel so that the team can understand your questions, concerns, and worries. The more team members know, the more Clinical Center services they can make available to you, including pastoral care, psychology/psychiatry, massage therapy, and community outpatient services.

### The transplant

The medications that are given before transplant can make some people feel unwell and affect their mood and coping. Some people have nausea, vomiting, fever, diarrhea, and fatigue. These symptoms, especially when they occur for a while, can strain both the person undergoing the transplant as well as his or her family. This is because the patient's energy level will be reduced and the patient will need more care from family members.

### What to do?

Some patients undergoing transplant may think they “should” be able to handle all their physical or emotional symptoms.

So while you might be able to handle some symptoms, it is important to not dismiss them when they get hard to manage. Please let your health care team know which symptoms are hard to cope with and how you are managing emotionally. Often, adjustments in your medications and treatments can help you feel better.

### Isolation precautions

During your transplant, you may have an infection that requires special isolation precautions. These precautions may require limiting your activity to your patient care unit as well as having visitors wear masks, gowns, and gloves.

#### What to do?

Many people find it helpful to keep themselves distracted with a variety of activities.

- ▶ You will have a television in your room, which is also a computer and DVD player. You can e-mail and video-conference with your friends/family on this computer.
- ▶ Recreation therapy staff can bring crafts and games.
- ▶ You can choose a book or movie to enjoy in your room from the Patient Library's large list.

Be sure to let your health care team members know if you feel isolated so that they can put the right supports in place.

### Guarding your privacy

Because many staff members need to know personal details about your day-to-day progress during the transplant, maintaining your sense of privacy in the hospital might be difficult for you.

You might also feel helpless when you need to rely more on others to help you with daily activities during the transplant process.

#### What to do?

Let the staff know if and when you need time to yourself, or when you prefer to be awakened for things such as temperature or blood pressure checks. If there are times when you do not want visitors (except staff that need to provide medical care), the nursing team can make sure that appropriate signs are placed on your door so that your wishes are respected.

### Leaving the hospital

Emotional distress can continue even after leaving the hospital. Those who have gone through a bone marrow or stem cell transplant often describe having some days where they feel better, and other days where they feel poorly. Some people find it harder to cope after leaving the hospital than they do in the first few weeks after transplant.

#### What to do?

Feelings of being up and down, frustrated, and a little sad are normal reactions after a long, intense hospital stay. It is very important that you share these feelings with your doctor, nurse, or social worker so that we can provide the best support to you.

### For families and friends

Each family adapts to the transplant process differently. Some families share care responsibilities easily while others express anger or blame regarding

“who does what.” Others may feel guilt for not being able to contribute as much, or feel that they want to do more.

### **What to do?**

It often helps for families and friends to delegate responsibilities ahead of time, so that decisions are not made under stress.

When possible, rotate responsibilities to allow all members to feel equally involved.

It also helps to have family meetings with the health care team when important transitions in treatment occur. This allows everyone to be equally informed and ask questions. When meetings are not physically possible, telephone conversions may work well.

### **Specific Issues for children and adolescents undergoing transplant**

When the transplant recipient is a child or adolescent, a parent will need to stay in the hospital overnight. Some parents find this stressful as well as physically and emotionally exhausting.

The transplant experience is different for every child and depends on his or her personality, specific medical course, and physical symptoms. Often, being separated from friends and family is difficult. Siblings who stay at home can feel left out and helpless in the process—feeling as though parents and friends now focus all their attention to the sibling undergoing the transplant.

During these times, the child or adolescent patient may direct anger and frustration at

parents or siblings, while at the same time feel guilty for these thoughts or behaviors.

### **What to do?**

- ▶ It is important for parents/guardians to try and get rest and maintain healthy eating and sleep patterns. For those who like to exercise, there are places in the hospital or at the Inn where parents can work out. The staff can help you to plan for some time away from the hospital during the day.
- ▶ It may help to bring objects of comfort and distraction from home to ease separation, isolation, and boredom. For example, bring games, a favorite toy/pillow, and e-mail addresses to maintain contact with peers.
- ▶ The NIH has a school, and the teachers work hard to coordinate each child's academic requirements with each child's home teachers or grade level. Your social worker can help you and your child connect with the NIH Children's School.
- ▶ For the children at home, it is crucial to keep as much routine or “normalcy” in their lives as possible to reduce anxiety. Arrange a time each day to call home so that you can help maintain consistency in their lives. When possible, caretakers should rotate responsibility between the patient and other children so that they can stay involved in each child's life. Talk to your social worker about sibling programs and other tips to help family members at home.

## Coping strategies

### ► Talk to your doctor and medical team about your feelings and needs.

These staff members can provide support and help you through these difficulties. Let the team know how you like to learn about medical information and how much information you want to receive.

Open communication also helps address changes in the recipient's health and symptoms and helps the recipient to adjust to the medication regimen.

### ► Accept support from family friends, and community

Families may hesitate to accept help from others so as not to be a burden. Families also might feel that they should manage it all on their own. The transplant process can be exhausting, and it helps to use whatever support they can to conserve their energy and resources.

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